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Joint United Nations Programme on HIV/AIDS

Summary

In response to recommendations of the Permanent Forum on Indigenous Issues, the Joint United Nations Programme on HIV/AIDS (UNAIDS) provided background information on the understanding of HIV/AIDS-related issues among indigenous peoples and an analysis of some key factors influencing vulnerability and the impact of HIV and AIDS on indigenous peoples in the context of social, cultural and economic development. Examples of initiatives on HIV prevention among indigenous communities were presented. UNAIDS presented a few issues relevant to HIV prevention and AIDS care and treatment among indigenous peoples to be discussed at the Forum. Recommendations were also made to the Forum in this regard.

* E/C.19/2006/1.

** The present document was submitted late in order to ensure the inclusion of the most recent information.

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I. Introduction

1. The present report was prepared by the Joint United Nations Programme on HIV/AIDS (UNAIDS) at the request of the Permanent Forum on Indigenous Issues to assist the Forum in its discussion of issues relating to Millennium Development Goal 6, Combat HIV/AIDS, malaria and other diseases, at its fifth session.

2. In talking about indigenous peoples, the present report draws upon the common understanding that has evolved in the international community of what is distinctive about indigenous peoples' experience. Central to that understanding is the notion that indigenous peoples are descended from the original inhabitants of a particular region, have a special attachment to that land and have a belief system that flows from that attachment. It is an attachment which pre-dates the establishment of modern States and territories, and which in many cases has been dislocated by the establishment of those jurisdictions and by more recent economic development. Because the relationship between indigenous peoples and their land is often neglected by mainstream economic development, the threat posed to that fundamental part of indigenous culture is a feature of the modern experience of many indigenous peoples.[1]

3. Indigenous peoples seek to maintain the historical continuity of their connection to land, and the cultural identity that accompanies it, in the face of other cultures that have become dominant by reason of colonization or occupation. In many countries, indigenous peoples are minorities and lack a voice within mainstream political institutions. To that extent, the experience of indigenous peoples is often one of marginalization within the countries in which they live and limited participation in the political process. They are excluded from the institutions that shape mainstream political, economic and social values.

4. How those factors play out in the day-to-day lives of indigenous peoples varies greatly across communities and countries. There are great differences in the extent to which particular indigenous communities have been able to maintain traditional ways of living, including traditional beliefs and practices. Some indigenous peoples still live in their own self-contained communities, often geographically isolated from major urban centres. Others struggle to reconcile traditional communal ties and values with the economic and social realities of the country in which they live. While their indigenous heritage may remain a central part of their identity in each case, the impact that has on their lived experiences may be radically different.

5. For that reason, any discussion about indigenous peoples as a single group necessarily involves considerable generalization that does not do justice to the enormous diversity in indigenous culture and experience across the world. That must be borne in mind when reading the present report. Of course, not all the issues discussed herein will be relevant to all indigenous peoples, nor will they affect them all in the same way. Nonetheless, the common themes in the experience of many indigenous peoples in different parts of the world shape how the HIV epidemic affects their lives and their communities. Those themes are explored in order to shed light on what can be done to reduce the spread and impact of HIV within indigenous communities.

II. Knowledge of the extent of HIV infection in indigenous populations

6. Very few countries have any reliable national surveillance data to indicate the true level of HIV infection among indigenous peoples. The available data are summarized in the annex. Only some surveillance programmes record the ethnicity of those tested and, even where infection levels in specific ethnic groups are identified, there is limited information about the specific patterns of HIV risk and the way in which HIV affects those communities. As with all data about HIV incidence and prevalence, caution must be exercised when drawing conclusions about the level of HIV risk based only on the results of HIV tests carried out on selected segments of the population.

7. The above is particularly true when trying to determine levels of HIV infection in marginalized groups, which is the case with many indigenous populations. Where people are geographically isolated, for example, or less able to access the health-care system, they may be missed by many HIV testing programmes. Moreover, where stigma and discrimination are associated with indigenous status, there is a disincentive for indigenous peoples to disclose their status if asked. Social and cultural taboos may also discourage indigenous peoples from disclosing forms of behaviour that place them at risk of HIV infection, if those behaviours are considered unacceptable in their communities.

8. There may also be good reasons for investigators not wanting to target marginalized groups, such as indigenous peoples, for specific HIV data collection. In the case of groups that are already disadvantaged and subject to stigmatization, the publication of data suggesting high levels of HIV infection within those groups can increase the stigma they experience, even though there might be high infection rates in other parts of the population. That concern has led some policymakers to avoid policy interventions focusing specifically on HIV in indigenous peoples, and instead incorporate those initiatives in other programmes, such as those dealing with sexual health generally. The possible negative consequences of data collection highlight the need for any research into HIV in indigenous communities to be carried out with care in order to avoid causing unintended harm to the people concerned.

9. Just as the collection of data on HIV in indigenous communities may lead to stigma and discrimination, the absence of data can lead to neglect or invisibility. The absence of reliable data about HIV infection in indigenous populations has sometimes made it more difficult for concerns about the impact of the HIV epidemic on indigenous populations to be given priority on national and international policy agendas. There is a risk that resources will instead go to HIV programmes targeted at populations where better data exist to demonstrate already high levels of HIV infection. Jurisdictions need to strike a balance between policies that seek to protect indigenous communities from being incorrectly perceived as an HIV threat to mainstream communities and the need to have reliable data on the impact of HIV in indigenous communities that can be fed into planning and resource allocation processes.

10. In this context, however, it needs to be emphasized that the number of diagnosed cases of HIV is only one measure, and often not the best, of the HIV risk faced by a particular community. The global experience with the epidemic has made

it clear that there are key factors that render some individuals and communities acutely vulnerable to HIV. Many, indeed most, of those risk factors are present in a large number of indigenous populations. They include poverty, marginalization, lack of political or social power, fragmentation of family and community relationships, geographical isolation, low literacy rates, poor general health, limited access to health care, drug use/injection and low individual and community self-esteem. Any one of these factors is enough to increase an individual or community's susceptibility to HIV infection. To have many of the factors present within one population group signals clear cause for concern about the impact of the HIV epidemic on indigenous populations and highlights the challenges faced in trying to reduce its spread within such communities.

III. Examples of strategies, policies and initiatives focused on HIV in indigenous populations

11. Just as there has been little consistent data collection on HIV in indigenous populations, there have also been only a relatively small number of specific policies and programmes implemented to address the spread and impact of HIV within indigenous communities. A few countries have adopted national strategies covering HIV in their indigenous populations, but this has generally happened only in better resourced countries, such as Australia and Canada. Many countries have done nothing to specifically address HIV issues in their indigenous peoples, while a small number of countries have embarked on small-scale initiatives. In some places, community-based and other non-governmental organizations have taken the lead in HIV prevention and care in indigenous communities, with greater or lesser degrees of Government support.

12. It has not been possible within the scope of the present report to undertake a full review of all past and present initiatives relating to HIV in indigenous peoples, and there would be value in studying such initiatives further to consider the lessons learned from what has been done. Examples of some of the key strategies and policies implemented to date are set out below.

Aboriginal strategy on HIV/AIDS in Canada for First Nations, Inuit and Metis people, March 2003

13. The strategy was developed by the Canadian Aboriginal AIDS Network, with funding from the Canadian Government, as part of the Canadian national strategy on HIV. It covers nine strategic areas, including community development, capacity-building and training, sustainability, partnerships and collaboration, legal, ethical and human rights issues, engaging aboriginal groups with specific needs, and holistic care, treatment and support.

National indigenous Australians' sexual health strategy, 1996-1999, and national Aboriginal and Torres Strait Islander sexual health and blood-borne virus strategy, 2005-2008

14. The above strategies address HIV in the context of indigenous sexual health generally and complement Australia's national strategy on HIV. There was a deliberate policy decision to position indigenous HIV initiatives within a sexual and reproductive health approach to avoid further stigmatization of indigenous

Australians and to recognize the need for significant improvements in indigenous sexual and reproductive health.

American Indian/Alaska Native initiative, United States Department of Health and Human Services

15. The American Indian/Alaska Native initiative is designed to integrate drug-use and mental health services with HIV primary health care for American Indian and Alaska Native communities. Six demonstration projects and a technical assistance centre comprise this five-year initiative, which began in October 2002 and ends in September 2007. Since American Indian/Alaska Native agencies operate under a federal policy that promotes self-determination for American Indian and Alaska Native peoples, the technical assistance centre respects the interests of American Indian/Alaska Native projects to develop culturally appropriate solutions to community, tribal and village issues and encourages solutions to come from the local level.

Indigenous peoples' development plan — Guyana, 2004

16. As part of its HIV/AIDS prevention and control project, the Government of Guyana implemented the indigenous peoples development plan. The plan identifies a range of factors that increase the vulnerability of indigenous communities in Guyana to HIV/AIDS, such as poverty, social disruption caused by mining, migration of young people, drug use, early sexual activity and certain cultural beliefs and practices. Among the interventions proposed are distribution of material on HIV translated into indigenous languages, voluntary counselling and testing centres close to indigenous communities, greater education for young girls and community development projects for young indigenous people.

Health of the indigenous peoples initiative — Pan American Health Organization, strategic directions and plan of action, 2003-2007

17. The plan of action covers indigenous health generally, but includes issues relating to HIV, particularly access to care and essential drugs. It notes existing inequities in health status and access to health care among indigenous peoples and other population groups in the Americas and outlines a plan of action to improve indigenous health status, including strengthening networks of intersectoral collaboration; incorporating indigenous perspectives and therapies in primary health care; promoting strategies that address the social exclusion of indigenous populations; and encouraging indigenous participation in the management of health services.

HIV/AIDS project for aboriginal youth — Public Health Agency of Canada, 2005-2007

18. The project, implemented in partnership with the Native Men's Residence, in Toronto, aims to increase awareness of HIV and promote safer sex among homeless aboriginal youth.

Management of HIV/AIDS in indigenous primary care organizations, Australia

19. A resource guide was developed by a group of indigenous Australians infected and affected by HIV. It was developed for use in remote and urban Aboriginal medical services and in other primary care services.

Australian Federation of AIDS Organizations Aboriginal and Torres Strait Islander gay, sistergirl and transgender HIV/AIDS — sexual health project

20. This long-standing Government supported project was established in 1996 and supports the indigenous work of Australia's national HIV non-governmental organization. In an epidemic driven primarily by sex between men, the project focuses on indigenous gay men, "sistergirls" and transgendered people. In addition to health promotion activities and advocacy, the project provides cultural awareness training for non-indigenous HIV workers and HIV training for indigenous health workers.

IV. Key factors affecting the impact of the HIV epidemic on indigenous populations

A. Relationship to land

21. If one of the key identifying characteristics of indigenous status is taken to be an attachment to ancestral land, then the displacement of that attachment due to economic and political developments in many countries of the world has a profound impact on the lives of indigenous peoples. Many indigenous communities are no longer able to live on the land from which they draw their cultural identity and have been forced to abandon their traditional ways of living as a result. That, in turn, affects in many ways how the HIV epidemic may be experienced in those communities.

22. The devastating consequences of colonization for the general health of most indigenous peoples has been well documented. Infectious diseases such as smallpox decimated many indigenous populations during the early phases of colonization, and that has been followed by dramatic increases in chronic disease brought about by the disruption to traditional indigenous lifestyles. In particular, diseases such as diabetes and chronic heart disease are now prevalent in many indigenous communities as a result of poor diet and unhealthy lifestyles in people whose preferred way of living is no longer tenable.

23. The forced transition to a lifestyle more compatible with the demands of modern economies has usually involved a relinquishment, in whole or in part, of the attachment to ancestral land. While some indigenous communities now live on reservations or in enclaves established in an attempt to preserve traditional lands, the extent to which those communities are able to retain traditional lifestyles is severely curtailed. Poverty, unemployment, imprisonment, alcoholism and drug use, including injecting, may be more common in some settings, as has been extensively documented and analysed in many studies. Moreover, the geographical isolation of the communities means that they have limited access to mainstream educational, health-care and public-health facilities. Each of the factors gives rise to a heightened risk of HIV.

24. Where the severing of their traditional relationship to land has resulted in the migration of indigenous peoples to urban areas, a similar range of social problems is evident. Indigenous communities within cities are generally marked by higher levels of poverty and other related factors that have an adverse impact on health. Their marginalization makes them more exposed to the risks of HIV transmission and harder to reach for HIV prevention and care.

25. Just as significant as the impact on lifestyle is the effect that dispossession of traditional land has had on the cultural and spiritual well-being of indigenous peoples. A community lacking in social cohesion, whose internal values are under threat, is not well placed to address the impact of HIV infection. Affected by the loss of land, territories and natural resources, which are fundamental elements for them to sustain themselves as peoples, many indigenous peoples' social and cultural capacity is also diminishing to address the challenges of HIV within their communities and to take steps to address the factors that increase the likelihood of HIV transmission.

B. Poverty

26. While there are of course exceptions, many indigenous communities are economically disadvantaged compared with other segments of the population. That is often a direct consequence of the disruption to subsistence on land that has characterized many indigenous cultures. The resulting loss of self-sufficiency has meant that many indigenous peoples are forced to move away from their community in search of work. Low levels of formal education mean that indigenous peoples may find it more difficult to obtain secure work and are frequently employed in lower paid jobs with little access to employer supported health schemes. Many who migrate from their traditional rural homes to urban areas end up living in poverty in urban slums. Although no longer geographically isolated, they have no sustainable livelihood and are still denied access to many basic services, including health care.

27. The correlation between poverty and the risk of HIV infection is well recognized and occurs at many different levels. Those living in poverty are less likely to have access to education, health care and other social resources. Many factors linked to poverty and deprivation of identity make indigenous peoples more vulnerable to sexual exploitation, or to become victims of trafficking in women and children. It may be difficult for people living in poverty to afford condoms or to insist on their use. Moreover, the absence of hope, often associated with poverty, deprives individuals of the psychological and emotional resources to protect themselves and others against HIV infection.

28. Because so many indigenous peoples are economically disadvantaged, it is important to appreciate the nexus between poverty and increased vulnerability to HIV. An understanding of that connection needs to inform HIV policies and programmes for indigenous communities, since the issues involved transcend concerns about health alone and include fundamental questions about indigenous status and the relationship between indigenous peoples and the larger communities in which they live.

C. Geographical isolation

29. As with any community living in a remote area, indigenous communities that are geographically isolated from major urban centres suffer particular disadvantages that increase their vulnerability to HIV infection. Limited access to schooling results in lower levels of literacy and increased vulnerability to HIV. Public health campaigns, including HIV prevention, may not reach geographically isolated communities, and if they do, they may have less relevance or practical application. Condoms may be difficult to obtain and expensive. Social problems in some geographically remote indigenous communities, such as alcoholism, drug use and domestic violence, may increase the risk of HIV transmission.

30. Access to health care is also a particular problem for all geographically isolated communities. Health facilities, if they are accessible at all, may be many hours away and may offer a limited range of services. Opportunities to obtain free or low-cost health care are more limited than in urban centres. Specialized HIV diagnosis, counselling and treatment are unavailable in most geographically remote areas, and concerns about confidentiality abound in small communities. For that reason, people in remote communities may be less likely to acknowledge their risk of HIV infection and, in the absence of readily available HIV treatments, have little incentive to learn their HIV status.

D. Different demographics and the disproportionate impact on young people

31. The demographics of many indigenous populations differ from the demographics of the general population in the countries in which they live. Many developed countries are facing issues associated with increased longevity and an ageing population. The combination of increased morbidity and mortality, shorter lifespans and recent improvements in health and education for many indigenous peoples has meant that most people in many of those populations are young people. Young indigenous people face particular issues of partial integration into mainstream society, disconnection from their traditional culture and dislocation from land.

32. HIV and sexual and reproductive health programmes need to be able to target those young people with acceptable and appropriate messages and support. That is complicated by their multiple identities as indigenous young people and as members of broader societies. Some cultural practices that put young people at increased risk also need to be addressed, because some issues are difficult to acknowledge and discuss openly.

E. Consequences of marginalization

33. While not all indigenous cultures are minority cultures in the country in which they live, most of them are, and awareness of being marginalized from mainstream social, political and economic culture is a feature of much indigenous experience. Some indigenous communities choose to live separately or in voluntary isolation from the mainstream, but others are excluded by reason of their different traditions

and culture. In either case, there is a sense of "otherness" attached to indigenous status and the risk of stigmatization within the broader community.

34. In the context of the HIV epidemic, it is now well accepted that marginalized groups within any society face a heightened vulnerability to HIV. That can be attributed to a range of factors. People already marginalized are more difficult to reach with HIV prevention messages and may be disempowered from taking steps, individually or communally, to protect themselves and others. If they already suffer stigma, they are less likely to acknowledge the risk of HIV infection and thereby expose themselves to further discrimination. Feelings of exclusion and an inability to exert control over one's own life are critical obstacles to HIV prevention.

35. Even within indigenous communities, there are groups that are more marginalized than others. As in many communities, indigenous or otherwise, the position of women and children may mean that they are especially vulnerable to exploitation and, in turn, to the risk of HIV infection. Marginalization may therefore be relevant at more than one level when considering HIV risks.

36. The marginalization of indigenous peoples has resulted in reduced access to essential health and welfare systems, employment, voluntary HIV counselling and testing services, sexual health services, antenatal care, including prevention of mother-to-child transmission, drug and alcohol services and HIV treatment care and support services. Those services form the foundation of successful HIV programmes and, while there are specific examples in some communities of attempts to tailor such services to the needs of indigenous peoples, they are not widespread enough to ensure the coverage required to produce desired HIV and health outcomes.

37. On the other hand, marginalization need not always have a negative impact on a community's capacity to respond effectively to the epidemic. Members of an indigenous community may be marginalized from the mainstream and yet despite that, sometimes, as part of efforts of identity-rebuilding, they may try to maintain a traditional sustainable way of life while coping with new challenges, including HIV and AIDS. In that way, identification as indigenous can sometimes be empowering rather than the opposite, and it should not automatically be assumed that greater integration of a marginalized culture into the mainstream will necessarily enhance its capacity to respond to HIV.

F. Different understandings of health and medicine

38. The international response to the HIV epidemic to date has been driven to a large extent by doctors and public health practitioners whose training, experience and understanding has come from Western medicine. Emphasis has been placed on ascertaining levels of HIV infection, reaching perceived "at risk" populations with prevention programmes and expanding access to antiretroviral therapies and other forms of treatment.

39. For many indigenous communities however, the Western medical tradition has no resonance. Such communities may have radically different understandings of disease and its spread, based on deeply held spiritual or traditional beliefs. Scientific explanations of HIV infection and transmission may not be easily reconciled with traditional conceptions of disease in those communities. Even where traditional

cultural practices may contribute directly to the spread of HIV, change is unlikely to occur just because Western science dictates that it should.

40. Traditional healers play a central role in many indigenous communities and shape their understanding about health and wellness. Often, wellness is understood to be much more than the absence of disease and may be inseparable from spiritual and religious dimensions. The community's faith in the healing power of traditional medicine may mean that traditional healers command a trust and respect far greater than that given to any doctor or health worker.

41. The different constructions of health and healing that exist in a large number of indigenous communities mean that many current HIV strategies are simply inappropriate for those communities and that interventions developed within the Western medical model are likely to fail. Different sources of trust and understanding within indigenous communities may need to be recognized, including the role of traditional healers and other spiritual leaders. If appropriate partnerships can be created to develop HIV prevention and care programmes that draw upon the cultural understanding of traditional healers and spiritual leaders and the respect they command within their communities, such efforts can be important forces for change to reduce the impact of HIV on indigenous communities.

42. It is more common for indigenous communities to take a "whole of health/whole of life" approach to dealing with health issues. In mainstream societies, health programmes are often vertical in nature, for example, dealing with HIV or heart health or diabetes. Indigenous knowledge and traditions favour dealing with people and communities in a more holistic way, and that approach is often in conflict with the single disease or health issue model. Many indigenous communities are facing a wide range of health and well-being challenges and are searching for ways to incorporate a response to HIV into existing initiatives and programmes rather than dealing with HIV as a single issue.

G. Low levels of participation in political and policymaking processes

43. Whether as a result of history, cultural tradition, size or other factors, few indigenous communities have strong representation in their national political institutions. While attempts have been made more recently in some countries to ensure indigenous participation in the policymaking process, at least in relation to issues concerning them, the more common experience of indigenous peoples is that they lack a significant political voice in the country in which they live.

44. When it comes to the formulation of effective HIV strategies, the low level of political participation by indigenous peoples is a serious impediment. Because the spread of HIV in any community involves complex questions of culture, sexuality and social relations, and because indigenous cultures, by definition, are different from prevailing or mainstream cultures, the development of strategies to reduce the impact of HIV on indigenous populations requires real and active engagement with those communities. Just as the contribution and involvement of people living with HIV has been central to an understanding of the epidemic and to the capacity to respond effectively, so too the involvement of indigenous peoples in the policymaking process will be essential to an understanding of how and why the HIV epidemic is affecting indigenous peoples, and what can be done to bring about change.

45. The political invisibility of many indigenous communities, however, presents a particular challenge in that regard. As long as indigenous communities remain outside the policymaking process, there is always a risk that they will be overlooked in HIV policies and programmes or that interventions will fail because they are not grounded in an understanding of indigenous culture and beliefs. The implementation of culturally sensitive and appropriate HIV strategies for indigenous peoples can be achieved only be if conscious efforts are made to draw indigenous communities into the policymaking process.

H. Increased burden of care already existing in indigenous communities

46. Because of poor levels of general health within many indigenous communities, many already bear a disproportionately high burden in terms of caring for family members and others who are sick. That burden is particularly heavy in remote communities with limited access to mainstream or community health-care facilities and associated services such as home care. In those communities, the burden of caring for those who are ill falls upon relatives and other members of the community, who may struggle to accommodate those demands because of their own poor health or socio-economic disadvantage.

47. Communities whose resources for care are already stretched by the burden of poor health are ill equipped to deal with the further strain placed on them by HIV. That compromises not only the quality of care available to those with HIV but also the capacity of the community to embrace and act upon the need for effective HIV prevention measures. The response to the HIV epidemic is more likely to be one of helplessness rather than a resolve to take steps to avoid HIV infection.

V. Leadership and advocacy actions the Permanent Forum could consider to reduce the impact of HIV on indigenous communities

A. Engagement with the global movement towards universal access to HIV prevention and care

48. The outcomes of the 2005 World Summit, the Group of Eight Summit and the World Health Assembly, in which calls are made for universal access to HIV prevention, treatment and care, present an opportunity for the Forum to work with United Nations organizations and international aid agencies to ensure that indigenous issues are considered in the strategies and action plans that support such initiatives. Indigenous issues cut across all aspects of HIV prevention and care. Universal access targets will not be met if the implementing agencies are unable to deal effectively with the significant development issues facing many indigenous populations.

49. The Forum currently receives regular reports from United Nations agencies. It could require that future reports include coverage of progress towards those universal access targets for indigenous communities.

50. However, such a requirement should not imply a passive role for the Forum. The outcomes will be more effective if the Forum can find ways to work in

partnership with those agencies and with others to assist in overcoming the significant barriers to access that exist in many communities and nations.

B. Participation in the development of models of HIV intervention that acknowledge the social and economic factors that affect indigenous populations

51. Models of HIV prevention and care that have proven successful in non-indigenous communities need significant modification if they are to be relevant to and successful among indigenous peoples. The Forum is well placed to work in partnership with United Nations agencies, donors and regional and national HIV coordinating bodies to ensure that policies and programmes are adapted to the needs of particular indigenous peoples.

52. The production of a set of resources highlighting effective partnerships and successful HIV interventions in indigenous communities would assist external agencies to better tailor their programmes.

53. Because so many of the factors that make indigenous communities particularly vulnerable to HIV relate not to health status but to their subordinate social, economic and political status within the broader societies in which they live, any policies on HIV in indigenous communities need to be seen in that context. Efforts to encourage voluntary HIV testing and acknowledgement of HIV risks, for example, are unlikely to succeed if steps are not taken at the same time to protect already stigmatized indigenous populations from further discrimination. Care and treatment for indigenous people with HIV cannot be provided effectively where general health care is already unaffordable or inaccessible. Some indigenous peoples who face increased HIV risks because they have no means of support except sex work, or who are vulnerable to human trafficking, cannot do anything in the face of those risks unless they are assisted in achieving a greater measure of economic self-sufficiency.

54. Addressing those broader social and economic determinants of vulnerability to HIV is a large task. Deep-rooted imbalances of that kind cannot be remedied easily or quickly, if at all. Nonetheless, in formulating HIV policies for vulnerable communities such as indigenous peoples, it is important to acknowledge the social and economic realities of the lives of those people. Poverty alleviation, literacy education and legal advocacy services may assist in addressing HIV risks just as much as targeted public-health education programmes. An integrated approach that situates HIV policy in this broader context is important to avoid the pitfall of seeing HIV as a stand-alone policy issue.

C. Advocacy for the availability of better data and information to drive HIV policy and planning in indigenous communities

55. The lack of accurate data and information to assist in HIV policy and planning for indigenous communities is a significant impediment to effective outcomes. While some jurisdictions have resisted the inclusion of ethnicity information in HIV surveillance programmes, fearing that this would increase the stigma and

discrimination experienced by indigenous populations, the absence of data makes planning and resource allocation extremely difficult.

56. The Forum could call for the development of a guidance paper by an appropriate United Nations agency to help surveillance system planners and policymakers to safely include the collection and reporting of ethnicity information in their second-generation surveillance systems.

57. Surveillance data is only one small part of the picture. The availability of social research data examining the particular context of risk in communities and the relative effectiveness of a range of HIV interventions is also a crucial part of the planning process. That appears to be lacking in many communities. Further research on HIV in indigenous communities, if properly focused, could assist in the implementation of appropriate and effective policies. Epidemiological data showing levels of infection and modes of HIV transmission can help to ensure that indigenous peoples are not overlooked in HIV planning and resource allocation and can assist in directing efforts to where they will have maximum impact. Research of that kind can also enhance understanding of what behaviours and environments place indigenous populations most at risk so that responses can be designed accordingly.

58. The possible harmful consequences of HIV research on indigenous populations must also be kept firmly in mind. Research in the area has to be approached with care. Participatory research models, involving research collaboration with indigenous communities and strict adherence to the principle of free, prior and informed consent, can help to ensure that research in this area does not cause unintended harm and end up being contrary to the interests of indigenous peoples.

59. The Forum could play a role in adapting and disseminating existing good practice documents that set out guiding principles for conducting research with, on and for indigenous communities.

D. Assistance in the development of strategies based on an understanding of indigenous culture, practices and beliefs

60. All communities have their own values and practices that must be understood in order to find effective ways of reducing the impact of the HIV epidemic. The values and practices of indigenous communities may be less well understood than others because they are usually separate from the mainstream and may have particular traditions that are unique to them. They may range from different beliefs about health and disease, and different values governing relationships within families, to different sources of trust within the community and particular meanings given to the roles of traditional healers or other spiritual leaders.

61. Given the differences that may exist between indigenous beliefs and ways of living and those of other communities, it is evident that effective HIV policies for indigenous peoples must be based on an understanding of the culture, practices and beliefs of each indigenous community. However, the difficult process requires at the outset an appreciation of what cultural factors may underpin particular forms of behaviour that place indigenous peoples at risk of HIV. Only then can culturally appropriate strategies for achieving change be developed within those communities.

67. The Forum is in a good position to advocate for the development of training programmes and resources that assist HIV policymakers and programme designers to take better account of those issues.

F. Fostering of indigenous community participation and informed consent in policy development

68. No effort to disseminate information on HIV and related prevention programmes involving sex, sexuality or family relationships within a community will be successful unless the individual members of that community decide themselves that information and HIV prevention are necessary. That emphasizes the fact that the principle of free and informed consent by indigenous peoples to interventions affecting them is not just rhetoric. Rather, it is fundamental to the success of HIV policies and programmes for indigenous peoples.

69. For this goal to be achieved there must be active participation by and engagement with indigenous communities as a central part of the policy response. This is important not only for the development of policies grounded in an understanding of the cultural context within each community but also to ensure that the members of the community involved accept that HIV policy measures affecting them are necessary and appropriate and are committed to supporting them.

70. Mechanisms for achieving a genuinely participatory process may vary greatly between different indigenous communities and may need to be tailored to accommodate ethnic, cultural and linguistic differences. Tensions between individual and communal interests and within traditional community hierarchies may need to be recognized and dealt with. External policymakers may still have an important role in this regard and in facilitating and supporting the implementation of HIV policies within indigenous communities. However, the relationship needs to be one of partnership and collaboration, extending beyond mere consultation, notwithstanding the power imbalances that may exist between indigenous populations and the societies in which they live.

71. The Forum has ample experience of fighting for meaningful participation of indigenous communities in all areas of policy and planning. It could bring that experience to the issue of HIV and provide leadership by establishing and promoting a set of standards that agencies, donors and jurisdictions could use to improve their performance in this area.

VI. Conclusion

72. To conclude on a positive note, it needs to be said that identification with a minority culture does not always have to be a disadvantage in this context. Any strong cultural identity can be a source of pride and can provide a powerful motivation for those who identify with that culture to take steps to protect the welfare of their community. There are certainly examples in the response to HIV where cultural minorities have been able to mobilize their communities to change behaviour that leads to the spread of HIV by drawing upon a shared sense of purpose and a common wish for their community to live and thrive.

68. In developing HIV policy responses for indigenous peoples, the potential for identification with indigenous status to be used as a positive force in that way should not be overlooked. Even in communities suffering the effects of cultural dislocation and fragmentation, a wish to preserve indigenous culture and identity can still emerge as a force for change, as long as such responses are nurtured and supported within the broader policy framework.

Notes

See ILO Convention No. 169 concerning Indigenous and Tribal Peoples in Independent Countries and E/CN.4/Sub.2/1986/7 and Add.1-4.

Annex

Summary of available surveillance and case-reporting data

1. The data available on HIV and AIDS in indigenous communities are very sparse. Only a few countries and states within countries with significant indigenous communities have been collecting passive and active surveillance data. The available data are summarized below. Many of the figures quoted refer to very small populations and the percentages can change dramatically with the inclusion of a single extra case making any analysis of trends very difficult.

2. Each report refers to indigenous peoples using different terminology. In each case the terminology of the report has been used. No offence to indigenous peoples is intended in quoting these terms.

Australia

3. Per capita rates of HIV infection in the indigenous and non-indigenous populations are similar and both rates declined in the period from 1995 to 1999. The rate of HIV diagnoses gradually increased from 4.0 per 100,000 in 2000 to 4.7 per 100,000 in 2004 for the non-indigenous population. In the indigenous population the rate of HIV diagnoses increased from 3.7 per 100,000 to 5.2 per 100,000 from 2000-2004. The rate of AIDS diagnosis in the indigenous population rose from 1.5 per 100,000 in 2000 to 3.6 per 100,000 in 2004. The corresponding rate for the non-indigenous population declined to 0.8 per 100,000 in 2004.

4. The main differences between the patterns of infection and risk in the indigenous versus non-indigenous population are: (a) a higher proportion of indigenous HIV infections are attributed to heterosexual sex than non-indigenous HIV infections (36 per cent for indigenous, 19 per cent for non-indigenous); (b) a higher proportion are attributed to injecting drug use (20 per cent for indigenous, 3 per cent for non-indigenous); (c) a higher proportion were among women (33 per cent of indigenous cases versus 10 per cent of non-indigenous cases).[a]

Canada

5. Of the AIDS diagnoses prior to 1994, 86.4 per cent were among white Canadians, 8.7 per cent among black Canadians and 1.3 per cent among aboriginal Canadians. Of the total AIDS diagnoses to 2003, 53.8 per cent are among white Canadians, 20.7 per cent among black Canadians and 14.4 per cent among aboriginal Canadians. The proportion of aboriginal Canadians among people diagnosed with HIV has remained relatively steady since 1998 at around 20 per cent, while the proportion of black Canadians among people diagnosed with HIV has increased from 9.3 per cent in 1998 to 14.4 per cent in 2004 (for those provinces/territories that submitted ethnicity data).[a]

6. Aboriginal peoples are overrepresented in the HIV epidemic in Canada and make up a growing percentage of positive HIV reports and reported AIDS cases. Injecting drug use continues to be a key mode of transmission in the aboriginal community. HIV has a significant impact on aboriginal women, the national rate of HIV among pregnant women in Canada is estimated at between 30 and 40 per

100,000 while one ongoing British Columbia study has revealed a rate of 310 per 100,000 among aboriginal pregnant women. Aboriginal peoples are being infected with HIV at a younger age compared to non-aboriginal persons. There is an increasing number of aboriginal peoples among newly diagnosed people with HIV.

7. It is important to note that only 29.4 per cent of the 12,600 positive HIV tests reported in Canada between 1998 and 2003 contained any information about ethnicity.[7]

New Zealand

8. A total of 1,212 people have been diagnosed with HIV since 1996, of whom 5.7 per cent of the men diagnosed and 0.7 per cent of the women diagnosed have identified themselves as Maori.[8]

United States of America

9. There are no HIV data presented. Several states with significant indigenous populations have only recently passed laws to require HIV surveillance.

10. AIDS data show that survival rates are lower for indigenous people with AIDS. In 2004, the estimated AIDS diagnosis rate among American Indians and Alaska Native adults and adolescents was 10.4 per 100,000 compared with 75.4 per 100,000 among African Americans, 26.8 per 100,000 among Hispanic Americans and 7.2 per 100,000 for white Americans. A risk-factor analysis for HIV diagnoses among American Indians and Alaska Natives from 2000-2003 shows transmission rates, for males, of 61 per cent from male-to-male sex, 11 per cent from male-to-male sex and injecting drug use, 15 per cent from injecting drug use alone and 12 per cent from heterosexual sex and, for females, 69 per cent from heterosexual sex and 29 per cent from injecting drug use.[9]

11. Data are difficult to interpret as American Indians and Alaskan Natives are often wrongly classified because of assumptions about skin colour, name or residence or because people being tested sometimes give false ethnicity information, fearing stigma and discrimination.

12. HIV risk in American Indian and Alaskan Native communities is compounded by higher levels of poverty, unemployment, substance use, sexually transmitted infections and violence.[7]

Central and South America

13. Indigenous communities and some ethnic communities tend to have higher rates of HIV infection than the general population. In Honduras in 1999, the HIV prevalence rate was six times higher among the Garifuna communities on the Atlantic coast than it was among the general population. Also in Honduras the Miskito indigenous community has been strongly impacted by the HIV epidemic. A seroprevalence study conducted at the end of the 1990s among the Kuna people in Panama indicated an HIV prevalence higher then the national average. The case among indigenous populations is similar in Canada. In Suriname, according to a

studies conducted in 1997, 17 per cent of all cases of HIV/AIDS in the country occurred among the ethnic group known as the Maroon, even though the Maroon account for only 10 per cent of the population.[5]

Notes

[1] *HIV, STD, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2005*. National Centre in HIV Epidemiology and Clinical Research, University of New South Wales, 2005.

[2] *HIV and AIDS in Canada: Surveillance Report to 30 June 2004*. Public Health Agency of Canada, November 2004.

[3] *HIV/AIDS Epi Notes: Understanding the HIV/AIDS Epidemic among Aboriginal Peoples in Canada: the Circumstances at a Glance*. Public Health Agency of Canada, 2004.

[4] *AIDS New Zealand*, issue 55, February 2005. University of Otago.

[5] CDC HIV/AIDS Fact Sheet: HIV/AIDS among American Indians and Alaska Natives. Centers for Disease Control, July 2005.

[6] Center for AIDS Prevention Studies Fact Sheet: What are American Indians and Alaskan Natives' HIV Prevention Needs?. University of California at San Francisco, January 2002.

[7] See the Regional HIV/STI Plan for the Health Sector 2006-2015. WHO/Pan American Health Organization, 2005.